

## WELCOME!

Through a mutual friend I met Roberta Omin, a writer who is compiling material for a book she has entitled *NECESSARY RISKING: Moving Through Life's Turning Points*. She sent me a paper explaining what she meant by "necessary risking" and the more I read, the more I knew that my life would fit right in with her description. I had just used other terminology, other imagery to describe my turning points up to then. I, in turn, wrote a paper for Roberta telling her about the major junctures I had encountered and how I had handled them. I gave her that paper during an interview that had been set up to see if part of my story would be suitable for her book. What a wonderful time we had together!

Roberta asked me to write about my decision to accept, rather than to fight, my crippling neurological disease called primary lateral sclerosis (PLS). I have spent much time thinking about my assignment since the interview and realize that my decision (which I keep current) rests on long established patterns of thinking and much experience. Before I delve into the PLS story, I need to tell you briefly who I am and how my mind works.

I am writing this in April, 2006. On the eighteenth of this month I will be 73 years old. Three months ago I moved into a nursing home to get the level of physical care that I need. Only my body is affected by PLS; my mind and spirit are fine. This brings me to a major point in my thinking: I see myself as body, soul (mind, emotions, personality) and spirit, with soul and spirit being eternal and the body destined for the grave – temporarily, at least.

My spirit and soul were not always fine. I was raised in a church that, while full of loving, sincere people, was also full of rules that I found stifling and scary, because breaking them was called sin and unconfessed sin at the point of death, we were told, would send us to hell. I didn't want to go to hell; I wanted to go to Heaven when I died! I had a close encounter with death in early childhood that left me with chronic illness and led to several operations, so dying seemed a possibility to me. And I was not perfectly keeping the rules; what if I died in an accident before confessing my sin? In my middle teenage years I became very nervous to the point of needing little green "nerve pills" to get through my school day.

The low point of my life came when I was a twenty-year-old college student. By then I had broken most of my church's rules. As a defense, I began to wonder if maybe there were no God; was it all a fable? Then came my defining moment, the event that changed my thinking – my whole life! – to this day. Suffice it to say that I had an encounter that same year with the living God. Not only did I realize that God existed, but I knew that he knew me and had made me his daughter forever! I had perfect assurance that I would go to Heaven when I died because my sins had been paid for by God himself on the cross of Calvary. I felt like a new person! I heard someone say just today that when you are confident of the future, you can face the present. That was true of me. With my ultimate future secured, I was ready for whatever might come my way. Being related to God, life was sure to be an adventure!

And it has been.

I love to use imagery as a basis for thinking and teaching. That's why I connected so well with Roberta's writings. The first quotation on the paper she sent me is from Anais Nin: "And the day came when the risk it took to remain tight inside the bud was more painful than the risk it took to blossom." I can picture that so well. I have been inside the bud, so to speak, many times and know what the squeezing feels like. I also know the glory of blossoming, of making the choice to break free. The similar image I have used is that of birth. I picture a baby positioned to enter the birth canal, a few hours of discomfort being the only thing remaining before the baby could really blossom. What if the baby had the ability to think and choose? What if the baby said, "It's too risky for me to go out into the unknown. I'll stay here with the familiar." There might be a little more growth, and then death. I

think of life as a series of chances to be born anew in many areas. Certainly I had a spiritual birth when I was twenty, but I have also had others involving decisions about jobs, illnesses (including PLS), and friendships, for example. On the other hand, I have seen people refuse to move to new levels where they could blossom. How sad!

Roberta described necessary risks to me as “risks we are impelled to take when caught in a two choice dilemma – metaphorically speaking, the choice of withering or being stagnant, or the choice of flowering and soaring psychologically, spiritually, emotionally or physically.” As I read this and the comments that followed, I was strongly reminded of a drawing I had once made and used as the basis for sermons and teaching. On one occasion when Jesus was talking with his followers, he said, *“Enter through the narrow gate. For wide is the gate and broad is the road that leads to destruction, and many enter through it. But small is the gate and narrow the road that leads to life, and only a few find it” (Matthew 7:13,14).* The thought of narrow and wide gates really captured my imagination. Some use this teaching to illustrate salvation, but I see it differently.

In my illustration I picture believers (people with faith in God; followers of Jesus; disciples) walking along the road of life together when they come to a place where the road splits. There are two signs at the start of the split. One says: “Narrow Gate to Life ahead. Travel lightly.” The other says: “Wide Gate to Destruction ahead. Unlimited baggage allowed.” Down the roads we can see people congregating around both gates. Those who choose the wide gate, which is certainly more popular, find that the land of Destruction is more confining than they had thought and that it fades away in the distance. Those who choose the narrow gate find the land of Life to be delightfully wide, giving them plenty of room to breathe, to expand. These folks travel along together, enjoying each other’s company, when – look at that! – the road splits again! There are the same two signs and on ahead people are milling around both gates. And so it goes throughout our lives on earth.

At least that is the way it has been with me, and I am still enjoying the trip. Along the way I developed a mindset – a personal philosophy – that made going through narrow gates, with all the risk that involves, the only logical thing to do. In answer to a question asked by Leo, my then future husband, I said, “My goal in life is to be what God wants me to be and to do what God wants me to do.” I felt such a sense of belonging to God and such gratitude for the way he lifted me out of my pit of despair that to say “Not my will, but yours be done” seemed normal for me. The Bible, books about the Bible and stories about people of faith were my textbooks as I became an avid student in God’s school of life. In addition I did a lot of thinking as I observed what was going on around me and what I was experiencing, trying to see things through the eyes of faith. “The best is yet to come,” I always thought – and I still do.

Leading up to my diagnosis of PLS, I will look back over my life in the area of health to see why I not only accept my illness, but actually welcome it (more about that later). Greatly influencing my thinking is the fact that as far back as I can remember, I have always been prone to sickness. The brush with death that I mentioned was due to pneumonia. I was only two-and-a-half years old. My parents did the best they could: they called the doctor. In turn the doctor did the best he could with the medicine available in 1935. My life was spared, but I was left with a chronic cough and chronic sinusitis that are still with me. People often ask me if I have a cold and I say “No, I’m fine. This is normal for me.” I can think of at least three major benefits I have had from my physical condition:

1. It kept me dependent on God. Often I had to pray for strength to carry out a commitment and my request was granted. It was a common thing for me to lose my voice. Many times when I was teaching and preaching I prayed for enough voice to give my message. Even though my voice was low and raspy, it was often clear enough to be understood at those times. Of course all this resulted in heartfelt expressions of thanksgiving afterwards. I was so aware that God knew me and the situation. God was personally taking care of me and I appreciated it.

2. It influenced the way I look at the Scriptures. Some people read the Bible through a mindset

that believes God promises his children perfect health. They find verses that seem to back up their premise and focus on them. I could never do that. When I read the Bible I found much about God's servants being sick, even with chronic illness, and this illness was seldom a sign of God's displeasure. Briefly during my teenage years I wondered if God were punishing me because I was often sick. Fortunately I concluded that this world is a place where sickness and death are normal, even for God's faith family. Why else would Heaven be presented as a place where there is no more death or mourning or crying or pain? While I also could not find in the Bible a "proper" way to pray that would guarantee healing, I could find plenty of tips and examples for how to endure all sorts of hardships, even for how to benefit from them. Looking at Scripture as I do has prepared me to be an encouragement to others who are ill or physically handicapped; it also opens the door for really appreciating the healing of the soul and spirit that God does offer in the Bible.

3. It bonded me to my mentor, the apostle Paul. I am convinced that Paul suffered from several kinds of physical problems, one of which he called his "thorn in the flesh" (1 Corinthians 12). Three times he pleaded with the Lord to remove the problem, and his request was denied. This is partly how I know that neither right living, proper attitude, nor correct wording of our prayers can guarantee physical healing. If the opposite were true, Paul would have been healed instantly! Instead, the Lord gave him new insight: *"My grace is sufficient for you, for my power is made perfect in weakness."* Paul did more than accept God's decision; he EMBRACED it! Listen to his joyful words: *"Therefore I will boast all the more gladly about my weaknesses, so that Christ's power may rest on me. That is why, for Christ's sake, I DELIGHT in weakness, in insults, in hardships, in persecutions, in difficulties. For when I am weak, then I am strong."*

Two things stand out to me in this story. First, Paul wanted Christ's power to be seen in him more than he wanted his own comfort; his aim was to glorify God. Second, the Lord empowered Paul with a sufficient amount of grace to help him go through whatever he had to face, including illness. I found Paul's enthusiasm to be contagious and wondered if God's grace would be sufficient for me, too. Many times when I was confronted with difficult situations I would pray, "Dear Lord, show me if your grace is sufficient for me now." And it always was!

Another thing I learned from Paul is the importance of living "with eternity's values in view," to quote a campfire song we used to sing in college. Two of my favorite quotes from his letters on this subject follow:

*– I consider that our present sufferings are not worth comparing with the glory that will be revealed in us (Romans 8:18).*

*– Our light and momentary troubles are achieving for us an eternal glory that far outweighs them all. So we fix our eyes not on what is seen, but on what is unseen. For what is seen is temporary, but what is unseen is eternal (2 Corinthians 4:17, 18).*

While Paul had in mind many kinds of problems when he wrote the above, illness was among them, and that is where I identified with him completely. I wrote tunes to both of these verses, strong, uplifting tunes that make Paul's thinking seem so desirable! As I sang the songs over and over, the message was sinking into my inner being. A test was coming; it arrived in June, 1996.

I had been getting regular mammograms for a long time. Three years earlier I had a biopsy on my right breast which proved negative. In 1996 the x-ray again showed something suspicious in the same area. Again I underwent a biopsy and was scheduled to visit the surgeon on Tuesday of the following week. All week I waited for a phone call telling me the biopsy results, but the call never came. That means it's cancer, I concluded. My suspicions were confirmed at my Tuesday appointment, for instead of putting me into an examining room where he could check my incision, the nurse ushered me into the doctor's office and pointed out a comfortable chair. "It is cancer this time," the doctor said, "but we have caught it early." He explained that he would perform a lumpectomy, also

removing the lymph glands from under my right arm as a precaution. He went on to say that they had taken the liberty of scheduling my surgery for Friday. "I couldn't possibly have surgery this week," I said. "I'm teaching an eleven week Bible class on Saturdays and the last class is this Saturday. So it has to be next week." He was surprised, saying most women want the surgery as soon as possible after hearing the news. Nevertheless, he called his nurse and asked her to reschedule my appointment. Finally she returned; the operation would be next Tuesday.

After that I began to feel really awkward. Before this, as time passed, I assumed we were waiting for the nurse to come with the hospital date. Now the doctor just sat behind his desk, making no effort at all to end the session. I wanted to leave, so I asked, "Don't you have other patients to see?" "I'll give you all the time you need," he replied. Then I understood: he had expected me to be devastated by the diagnosis and was kindly giving me time to recover. "I'm fine," I said, "but I have things to do. I'll see you Tuesday." And I left. One thing I did that week was practice what I call "looking to the end." I thought, "What is the worst that could happen with this illness?" I concluded that it could end in death. "If so, would that be all right?" I asked myself. I said it would, because death would simply usher me into my eternal Home. If the worst could be accepted, anything less would have to be all right too. Therefore, I had nothing to worry about, did I?

I taught the class on Saturday, convinced that I had made the right decision in doing so. I told the class members about the cancer and the coming surgery. In fact, I told a lot of people. Then Tuesday came. I went into the operating room with a longtime favorite Bible verse on my mind: *I am the Lord, your God, who takes hold of your right hand and says to you, Do not fear; I will help you (Isaiah 41:13)*. I squeezed my right hand, assured that my God was with me. I was human; humans get cancer. Here was another chance for God's grace to shine.

An amazing thing happened in my hospital room that evening. Six or seven of my dearest friends, some from the Saturday Bible class, came to visit me one by one, arriving in such close intervals that they were all there together. It looked like a prearranged meeting, but it wasn't; some of them didn't even know each other before that night. Each of my visitors was a person of faith, and each entered the room soberly, gingerly, expecting to commiserate with and encourage me. True, they had no way of knowing what my physical condition would be like: would I be in much pain or too tired to have company, for example? But my delight as the group gathered showed all over my face. Soon we were laughing and praising God, having such a good time together. They left with smiles on their faces, encouraged to know that the spiritual principles I lived and taught had held up even through breast cancer. God's grace had been sufficient for me once again.

As a followup to surgery, I had a course of radiation treatments that summer. Monday through Friday, week after week, I would go to the clinic and wait for my name to be called. Then I would go into a dressing room, strip to the waist, put on my gown and get the treatment. I say "my gown" because I wore the same one every day I was there. On the first day at the clinic I was given the gown, packaged in a plastic bag with my name on it. I was also assigned a cubicle in which to store the bag. I would look at all those plastic bags with names and think, "Every one of those people has had cancer." Somehow I felt privileged to be one of them, as if we were related. I could imagine a new credibility coming into my teaching and preaching as a result of my having had cancer, and it did.

And so the whole episode was behind me, though my deformed body did not let me forget it. I did not join a support group because I felt no need to do so, nor did I have time to take on another project. Once I walked with my daughter Marty in a fund raiser for breast cancer research.

Then I found some other strange things happening in my body. Occasionally when I was talking my tongue seemed to get stuck in my mouth and I would stumble over my words. I believe this was the first outward sign of PLS, which had probably been working in my brain for years. In June, 2002 phase two began, involving my legs: a jolt that felt like a severe electric shock suddenly hit my left shinbone, causing me to stumble. In July I began to fall and in September, during a complete

physical examination, I told my doctor all about it. In July of 2003, after many tests from two neurologists and more falls, including one in which I broke my hip, PLS was mentioned for the first time. "It's a rare progressive disease that cripples rather than kills," my doctor explained. "The disease affects the legs, the arms and the muscles involved in swallowing and speaking." He said there was no cure and no research going on. The doctor also felt that it was no longer safe for me to drive. "Then I will never drive again," I said. Those were two big blows to receive at once! I was certainly shaken, but by the time I walked out of the building with my son George, I said, "It's all right." Amazed, he asked, "You processed all that in ten minutes?" "It wasn't ten minutes, George," I answered. "It was a lifetime and ten minutes."

That was so true! My "long established patterns of thinking" and the many cumulative experiences I have had with my Lord held me in good stead as I embarked on another adventure with God. I already knew God's grace would be sufficient for me and that life on the other side of this narrow gate would somehow be wider than ever. "Looking to the end" showed me a different picture from what I saw with the cancer incident. At first I had the feeling that I would be dying soon, in a year, perhaps, and I had previously handled that thought. Now a new scenario emerged: would I be willing to be alive longer than expected, to endure years of diminishing ability with an alert mind, ending up in a nursing home totally cared for by others? If that is how God wants me to glorify him, I concluded, then it was indeed all right with me.

My neurologist sent me to a doctor at Mt. Sinai Hospital in New York City for a second opinion and then gave me further testing in 2004. All of that plus the progression of the disease still pointed to PLS as the correct diagnosis. Right now I cannot walk at all; I ride in a Powerchair to get around. Nor can I talk; I type on a Lightwriter, write on my computer or use gestures if I need to communicate. My arms and hands are stiffening and I am fed through a feeding tube in my stomach. My chronic cough and sinusitis are still present with me. I live in a beautiful room in a nursing home where I get good care and plenty of company. I believe I am exactly where God wants me to be. I am happy and content.

I feel like I am taking two "necessary risks" at this time. The first is to accept PLS, rather than fight against it, either by denial or by going on a campaign to eradicate the disease in myself and others. Some might think I am "giving up," that I should do whatever I can to extend my life on earth, no matter how much energy it takes. The second is to reveal my thinking, not only to family and friends, but also to the general public. When feelings are put on paper there is always the chance that they will be misunderstood or criticized. And yet as I write this paragraph, the risks vanish when compared with the eternal benefits of doing the will of God. In this whole area, again I feel such a kinship with the apostle Paul.

A traveling missionary, Paul was concluding his third trip when he sensed that things were changing. He told a gathering of church leaders, *"And now, compelled by the Spirit, I am going to Jerusalem, not knowing what will happen to me there. I only know that in every city the Holy Spirit warns me that prison and hardships are facing me. However, I consider my life worth nothing to me, if only I may finish the race and complete the task the Lord Jesus has given me – the task of testifying to the gospel of God's grace"* (Acts 20:22-24). Paul was not giving up by going to Jerusalem; he was moving on, moving forward in the mission God had given him to do. His life was undergoing change, and that was fine with Paul, even if his friends wanted more of the same. Paul actually lived quite a few more years after going to Jerusalem, but most of them were spent as a prisoner in various cities. Through writing and visits, the work of God thrived from Paul's cells!

In a different sense I, too, am being confined at the end of my life. My desire is the same as my mentor's: to finish my race well. Besides letting my life exhibit the truth of the gospel, I believe I am to write. So that's how I have chosen to spend my days and my energy. After my hands no longer function, I will have to stop, just as Paul eventually wrote his last letter. Whether we live or die, whether we are free or imprisoned, whether healthy or incapacitated, people of faith belong to the Lord. How good it is to let the details up to God!

Paul's patterns of thinking came from keeping his eyes on Jesus. He became so Christlike that he could say, *"Follow my example, as I follow the example of Christ" (1 Corinthians 11:1)*. Twice in the examples I have used in this essay Paul says "I consider..." surely revealing his own thoughts; both reflect the attitudes of Jesus. Paul considered our present sufferings not worth comparing with the glory that lies ahead for us. Jesus, *"for the joy set before him endured the cross, scorning its shame, and sat down at the right hand of the throne of God" (Hebrews 12:22)*. Paul's desire to finish the race, the purpose for which he was here, was greater than the desire to prolong his earthly life. Jesus also had gone to Jerusalem, knowing it was a dangerous place, because of a sense of destiny. A few days before his death, Jesus said, *"Now my heart is troubled, and what shall I say? 'Father, save me from this hour?' No, it was for this very reason I came to this hour" (John 12:27)*. Jesus did not resist arrest or fight at his trial. On the cross he was able to say, *"It is finished!"* Jesus finished his race; Paul finished his; and I want to finish mine.

One thing Paul tried to avoid was talking about his own experiences, but sometimes he had to do it for the good of those to whom he was writing. Some people today accuse Paul of being proud, of boasting. What a misunderstanding! But that is one of the risks of writing: it can be interpreted in so many ways. It can even be explained away as of no practical value. This is often done by putting Paul on a pedestal, as if he were more than human. "His way of living was fine for him," these people think, "but we can't be expected to attain such high standards. After all, he was an apostle and we are ordinary folks." I always thought of Paul as an ordinary person whose philosophy of life I could adopt, if I wished. And I did, which is why I call him my mentor. More than twenty years ago I wrote a song about believers with these words:

Ordinary people, touched by God.  
We're ordinary people, touched by God.  
The life we live is not our own;  
We've been bought with a price and to Him belong.  
We're ordinary people, touched by God.

This is what I call a "two sides off the coin" teaching. Yes, we are ordinary, fully human. On the other hand, anyone touched by God is bound to be extraordinary as well, a human being with a divine spark inside that glows dimly or brightly according to how much attention we give to that spark. There is nothing in my way of thinking that is not available to any person with faith in God.

A new image has come to my mind recently that helps me express how I feel. I picture PLS as a person who has come to live in my house, that is, my body. I was given no choice in the matter. I don't know where he came from or who sent him, but I do know that he is here to stay. He intends to make his presence known more and more until he has taken over completely. What's more, he has the power to kill me, if he wants, through choking or pneumonia caused by aspiration or by ways I don't even know about. Because I have a Home waiting for me when I leave this world, I am not afraid of being evicted from my house. The problem that remains is how to get along with my "guest" on a daily basis. I can't ignore him, nor do I want to become obsessed with him. I could accept him, but I'm thinking there is a better way. I've decided to welcome him, just as long ago I welcomed God's Holy Spirit who moved into my house to take over. I can let God deal with my newest guest, since God knows my house so well.

I expect that peace will rule in this arrangement, a peace that is not easy to understand. One day, if I am not forcibly evicted, I will be crowded out of my house, move through my last narrow gate, and enjoy the incredible wideness on the other side. PLS will be part of the baggage I cannot take through that final narrow gate, along with my body itself. Meanwhile, welcome, PLS! You are part of my adventure with God.